Quality of life in chronic diseases, the role of the family

(Jakość życia w chorobach przewlekłych, rola rodziny)

Barbara Bogusz [1,A,D], Monika Mazurek [1,F], Zbigniew Kopański [2,E], Iren Brukwicka [1,B], Grażyna Tomiak [1,C,E], Baigalmaa Urjin [3,C,E]

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Abstract – Introduction. Everyone, especially the sick, wants closeness and understanding. He seeks contact with his nearest and dearest, with his family. The family becomes a support for the sick person. A sick person usually expects a balanced interest and willingness to help when he or she requests it. At the same time, especially a chronically ill person needs respect, acceptance of limited physical abilities, various forms of disability often resulting from the progress of the illness, acceptance of a long stay in bed, sometimes its emotional lability.

Aim of the study. The aim of the work was to briefly discuss the importance of quality of life, with particular emphasis on the quality of life in a chronic disease, on characterising the contemporary significance of the family and its role in the life of a chronically ill person.

Selection of materials. The search was conducted in the Scopus database for the period 2003-2019, using the terms *chronic disease, quality of life in chronic disease, the family, its role in the life of a chronic patient*. From the literature found in the Google Scholar database, studies were selected which, in the opinion of the authors, would be most useful in the preparation of this study.

Conclusions. The family should be a sensitive observer of the patient's condition. This applies especially to sick children. Parents must not allow the child's confidence to be reduced. They must be a reliable partner in discussions with the sick child. They must know the child's needs and expectations skilfully. This will in many situations increase proximity and understanding.

Key words **-** chronic disease, quality of life in a chronic disease, family, its role in the life of a chronically ill person**.**

Streszczenie – Wprowadzenie. Każdy człowiek zwłaszcza chory pragnie bliskości i zrozumienia. Szuka kontaktu z najbliższymi, z rodziną. Rodzina staje się dla chorego wsparciem. Chory od najbliższych zazwyczaj oczekuje wyważonego zainteresowania, gotowości pomocy w sytuacjach gdy o nią poprosi. Jednocześnie, zwłaszcza chory przewlekle potrzebuje szacunku, akceptacji ograniczonych możliwości fizycznych, różnych form niepełnosprawności często wynikającej z postępu choroby, akceptacji długotrwałego pobytu w łóżku, niekiedy jego labilności emocjonalnej.

Cel pracy. Celem pracy było krótkie omówienie znaczenia jakości życia, ze szczególnym zwróceniem uwagi na jakość życia w chorobie przewlekłej, z charakteryzowania współczesnego znaczenia rodziny i jej roli w życiu przewlekle chorego.

Dobór materiału. Poszukiwania przeprowadzono w bazie Scopus za okres 2003-2019, używając pojęć *choroba przewlekła, jakość życia w chorobie przewlekłej, rodzina, jej rola w życiu chorego przewlekle*. Ze znalezionego w bazie Google Scholar piśmiennictwa wyselekcjonowano opracowania, które zdaniem autorów byłyby najbardziej użyteczne w przygotowaniu niniejszego opracowania.

Wnioski. Rodzina winna być wrażliwym obserwatorem stany chorego. Dotyczy to zwłaszcza chorujących dzieci. Rodzice nie mogą dopuścić do obniżenia zaufania u dziecka. Muszą być wiarygodnym partnerem w rozmowach z chorym dzieckiem. W sposób umiejętny muszą poznać potrzeby i oczekiwania dziecka. To w wielu sytuacjach zwiększy bliskość i zrozumienie stron.

Słowa kluczowe – choroba przewlekła, jakość życia w chorobie przewlekłej, rodzina, jej rola w życiu chorego przewlekle.

Author Affiliations:

1. Collegium Masoviense – College of Health Sciences, Poland
2. Faculty of Health Sciences, Collegium Medicum, Jagiellonian University, Poland
3. National University of Mongolia, Mongolia

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B. Gathering and listing data
C. The data analysis and interpretation
D. Writing the article
E. Critical review of the article
F. Final approval of the article

Correspondence to:

Prof. Zbigniew Kopański MD PhD, Faculty of Health Sciences, Collegium Medicum, Jagiellonian University, Piotra

Michałowskiego 12 Str., PL- 31-126 Kraków, Poland, e-mail: zkopanski@o2.pl

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I. CHRONIC DISEASE

There is no single commonly accepted definition of chronic disease in medicine. At its simplest, it can be described as a disease that lasts for a long time and is characterised by relatively slow progress of lesions. However, the most precise definition of this disease seems to be that adopted by The National Commission on Chronic Illness.

According to this definition, chronic diseases are considered to be disorders or abnormalities having one or more of the following characteristics: they have a long-term course, their course and treatment are not clearly defined, they leave an impairment or dysfunction after transition, they require specialist rehabilitation and supervision as well as observation and care. [1,2]

Chronic disease is also sometimes referred to as [3]:

- a disorder of long duration which may be progressive and poorly predictive or related to a relatively normal course of life despite abnormal physical or mental functioning;
- an adverse condition that lasts for more than three months a year or requires continuous hospitalisation for at least one month;
- a disease that lasts for a significant period of time or is recurrent, that is to say, there are further sickness spells in the long term;
- permanent, irreversible, progressive changes damaging the system, permanently reducing its efficiency and effectiveness, mainly in the so-called acute, but also chronic states, as one and the same continuous process of destruction.

II. THE CONCEPT OF QUALITY OF LIFE

Quality of life is most often compared with wellbeing, satisfaction, happiness. Many excellent philosophers and sages have been interested in quality of life issues.

Already in ancient times, Aristotle paid attention to man's desire to obtain the greatest possible pleasure and satisfaction from his choices and well-being throughout his life.

In turn, for Hippocrates, happy life was to be expressed through a state of internal balance [6]. He proclaimed that happiness is the ability to achieve a state of internal balance, i.e. the relationship between what surrounds us and the individual way of life.

Therefore, every human being has an influence on shaping his or her life and thus its quality. Such skills should be shaped in the upbringing process.

The theory of reasonableness, initiated by Heraclitus, has led many of his successors to continue to reflect on the possibility of further improving life and making it more enjoyable.

The result of these reflections was a philosophy of Democritus indicating satisfaction as the highest good, where reason is the means of obtaining it.

Socrates, on the other hand, saw happiness in virtue, which meant nothing more than bravery, physical strength, fitness and knowledge.

Similarly, Plato's views confirmed that happiness is shaped by everyone's way of thinking and looking at the world, by moral standards, by a hierarchy of goals and values.

In many other philosophical concepts, quality of life was most often identified with welfare, defined as the difference between the sum of all pleasures and the sum of all sufferings that a person experiences during his/her life [4-6].

One of the most frequently used and commonly quoted definitions of quality of life is the one formulated by the World Health Organisation in 1994. According to this definition, quality of life is defined as "an individual's perception of his or her position in life in the context of the culture and systems of values accepted by the society in which he or she lives and in relation to his or her life goals, expectations, interests". [7].

In addition to the generally formulated definition of the concept, there is also a specification of these spheres of life. These are, above all: physical and mental health, social relationships, the level of independence from others, the individual's personal beliefs and the impact of these beliefs on the environment in which the individual lives [8,9].

In defining quality of life, reference is usually made to both objective and subjective quality of life indicators.

Objective categories of the quality of life dimension include: standard of living, material and living conditions, health, participation in public life and even having a disability, i.e. the subjective assessment of one's own life situation by a particular person and comparing it to that of others.

The following can be considered as subjective indicators: the degree of satisfaction with the fulfilment of one's own physical, social and psychological needs, as well as satisfaction with the individual's life achievements, and his/her participation in social structures [7,10].

In turn, by measuring quality of life - as the ability to live a normal life - with the social indicators of the term, it is measured by activity in all areas of social life, such as work, leisure time, family income and the social environment.

Modern society in the 21st century is moving away from many of the values valued in the past. "In today's reality, perceiving quality of life is first and foremost: - satisfaction from work, - a happy marriage, - optimism in life, - the ability to feel joy, - satisfaction in personal life (including gender), - financial stability". [11].

Quality of life studies allow for better perception of the patient's disease situation and are aimed at, among others [9,12,13]:

- to obtain as much data as possible on different areas of a patient's life;
- the involvement of the patient, his family and the therapeutic team in assessing the patient's situation;
- identification of areas of patient's activity requiring improvement;
- help in making the right therapeutic decisions and approaches.

Increasingly in recent years, in clinical research, but also in everyday practice, in addition to the biological and medical assessment of a patient's condition, quality of life is also assessed in relation to his or her health, that is to say, the impact that disease and patient treatment have on his or her physical, mental and social functioning.

Better assessment of individual quality of life parameters allows to improve communication with the patient by getting to know his personal problems, perception of the disease, as well as solving psychosocial problems important from the therapeutic point of view [10]. It also allows to determine the effectiveness of treatment over a longer period of observation, not only in relation to factors such as mortality, but also to other health events, such as health-dependent quality of life and lifestyle, which are particularly important for chronic diseases [11-14].

III. QUALITY OF LIFE IN CHRONIC DISEASE

The assessment of the quality of life of patients with chronic diseases is particularly important in treatment procedures. This usually concerns incurable diseases, where the patient most often has to deal with the disease and its treatment for the rest of his or her life. A frequent consequence of suffering from a chronic disease is frequent isolation from the environment, suffering and, in many cases, loneliness. The ailments which the disease brings may persist for years, usually gradually progressing [15].

Like any disease, a chronic disease also has major negative consequences that affect the various dimensions of a patient's life. They may be permanent or temporary: the need to change lifestyle, the need to prepare for long-term treatment, problems in understanding the professional terminology used in medical procedures [10,11,16].

Chronic disease triggers negative emotions in the patient, significantly worsening their quality of life. First of all, the patient's mental well-being is reduced. The mood is drastically reduced, aggression and irritability, anxiety, despair and indifference increase.

The patient is increasingly convinced of a strong dependence on the disease, and fear for his or her own health is growing, which may result in emotional problems. Such patients often lose the will to live and the will to fight the disease [15-18].

They often have processes that make the assessment of their health very different from an objective one.

There are situations in which patients are not aware of the development of their illness, do not know the prognosis and are not aware of the existing methods of its treatment.

There are also patients who know a lot about their disease and are strongly motivated to fight it. The way the patient himself evaluates his illness also has a strong influence on the treatment procedure.

This assessment consists of [15-20]:

- perception and assessment of disease symptoms;
- to learn how to deal with the physical, mental and social consequences of the disease;
- to assess his ability to function normally or to know how to gain control of the disease.

In studies on the quality of life of chronically ill people, the personality of the patient itself is also important, and the environmental conditions in which he or she lives may also be important. These factors greatly influence the effectiveness of treatment in chronic diseases [20].

IV. FAMILY

In a common understanding, a family is a basic social unit, a married couple with children or - most often in the countryside - grandparents, parents and children living under one roof [21].

From the encyclopaedic point of view, it is a form of collective life, appearing in historically and culturally diverse forms; the unambiguous definition of the family is a difficult and controversial issue. The essence of a family is a type of social bond: marital and parental, and in some types of families, also a bond of affinity. [22] The family occurs in all societies and epochs, it performs several basic functions in the life of society, the most important [21,22]:

- procreation, i.e. ensuring the biological continuity of society;
- socialisation, i.e. introducing the young generation into the norms and mechanism of collective life, caring for them and preparing them to play social roles themselves;
- maintaining the cultural continuity of society by passing on cultural heritage to future generations;
- running a household and in many cases also production activities (especially in agriculture);
- organising the lives of their members, exercising social control over their behaviour, ensuring their emotional balance, mutual assistance and care in the event of illness, old age, etc.

However, regardless of the scope of the study and the way in which the family is analysed, it is an essential form of functioning of individuals and (more broadly) of society at large. The family has existed since ancient times in most cultures, in all human communities. The foundation of social bonds between the family has always been, and still is, the relationship between spouses, the relationship between parents and children, and the relationship between children. These relationships between family members are most often of a direct nature, they are oriented towards cooperation rather than competition and have an emotional colour [23].

It is pointed out that man - understood as a social being - has an innate need to create close and strong emotional relationships, that is, those that are able to satisfy his need for security, love, functioning in a social group as well as the approval of that group, etc. Full satisfaction of these needs is feasible in a healthy, stable and properly functioning family with clear and well-shaped interpersonal relationships and a high level of understanding [24].

A number of criteria which may be taken into account in assessing the type of family are listed. The most commonly used are [25]:

- number of family members (small - parents with one child or large - parents with three or more children; two-generational - parents and children or multi-generational - grandparents, parents, children and sometimes grandchildren);
- organisational forms (full - two parents with at least one child, incomplete - one parent missing, reconstructed - one parent remarried); - place of residence (urban or rural family);
- source of livelihood (peasant, working and intelligent - this criterion is currently used less frequently).

In turn, Brągiel *et al.* distinguishes the following types of families [21]:

- small family - that is, marriage and underage children; personal contacts are limited to the closest family members;
- family as a friendly group - a form of voluntary community of parents and children (without formal marriage) or an economic and residential community of married couples (most common in the USA, the Netherlands);
- large family - it is generally found in rural environments; it is characterised by a large household, a community of generations, and the domination of family ties;
- large modified family - a multi-generational family, usually living in one house (possibly grandparents live nearby, but all have a strong family bond).

Describing a contemporary Polish family, it is defined as a small family, occupying an independent flat and running its own household. In the family, its institutional character disappears in favour of a more personal, intimate one. The male and female roles become less clear and the division of functions performed in the family by husbands and wives is more fluid. The distance between spouses is fading, just as the distance between parents and children is fading. Children in adolescence are often treated as equal partners. In the family, tolerance of differences between generations increases and roles are not rigidly defined [21,24].

Everyone, especially the sick, wants closeness and understanding. He seeks contact with his nearest and dearest, with his family. The family becomes a support for the sick person. Usually a sick person expects a balanced interest and willingness to help when he or she asks for it. At the same time, especially a chronically ill person needs respect, acceptance of limited physical abilities, various forms of disability often resulting from the progress of the illness, acceptance of a long stay in bed, sometimes its emotional lability. It is a bad thing when a family, in the name of taking care of a patient, stops talking to the patient about his illness, tries to activate the patient at all costs, trying to distract the patient's attention from his suffering.

The family should be a sensitive observer of the patient's condition. This applies especially to sick children. Parents

must not allow the child's confidence to be reduced. They must be a reliable partner in discussions with the sick child. They must know the child's needs and expectations skilfully. This will in many situations increase proximity and understanding. [26-28]

V. REFERENCES

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